Clinical Outcomes Data Reporting and Research Program (CORRP) Privacy Statement

Privacy refers to the protection of an individual's personal information and the right to control how it is collected, used, disclosed, and stored.

What does 'data protection' mean at Monash?

In the context of CORRP projects (including Clinical Quality Registries (CQRs)) at Monash University, data protection refers to the systems, safeguards and practices Monash uses to prevent unauthorised access, loss, or misuse of information. It ensures that data remains secure, accurate, and available when needed, including through backup, recovery, and compliance with legal obligations.

What is data privacy, and why does it matter?

Data privacy is about individuals' rights to control their personal information — how it is collected, used, stored, and shared. It ensures people are informed, can give consent, and have access to their own data. Privacy is essential for building trust and respecting the dignity of individuals.

How do data protection and data privacy work together?

- Privacy is about the right to control your personal information.
- Protection is about the means to secure that information.

Your Privacy Matters

Monash University is committed to upholding privacy rights and protecting personal data through secure systems and responsible practices. We follow strict data protection protocols aligned with the Australian Privacy Principles. Your information is stored securely and only accessible to authorised personnel.

Monash University's Privacy Compliance Framework is available at Home - Data Protection and Privacy , which includes the Data Protection and Privacy Procedure and the Research Data Protection and Privacy Collection Statement.

What Information is Collected?

We may collect:
- Personal details (e.g., age, gender, postcode)
- Clinical data related to your treatment or procedure
- Patient-reported outcomes and experiences (PROMs and PREMs)
- Information about medical devices used, if applicable

How is Your Information Used?

Your data is used to:
- Monitor and improve healthcare quality and safety
- Identify trends and best practices
- Inform policy and clinical guidelines
- Support research and innovation in healthcare delivery

Your Rights and Choices

- *Consent:* Participation is voluntary. You will be informed about the project and then have a specified amount of time to opt out of the project.
- *Access:* You can request access to your personal information held by the project.
- *Withdrawal:* You can withdraw your consent at any time, and your data will no longer be used in the project

Data Sharing

To maximise the benefits of the project, your de-identified data may be shared and/or linked with:

- Healthcare providers and institutions for benchmarking and quality improvement
- Approved researchers conducting ethically-approved studies
- Government health agencies for healthcare system performance monitoring
- Safety and quality monitoring of high cost or novel medical devices and pharmaceuticals

Important Notes

- Shared data will be **de-identified**, meaning it cannot be used to identify you personally.
- Identifiable data (i.e. sensitive and personal information) will only be collected where reasonably necessary to conduct essential project functions or other activities as approved by a Human Research Ethics Committees (HREC). Such information is only accessible by Monash staff who require access to such data for operational requirements.
- Any data sharing complies with the **Australian Privacy Principles** and relevant legislation, including the **Privacy Act 1988 (Cth)**.
- We do **not sell** your personal information or share it for purposes other than those outlined above, such as commercial marketing purposes.

Data Retention and Destruction

Your personal health information will be retained in accordance with Australian legal and ethical standards:

- Adults: Data will be retained for a minimum of 7 years from the date of the last entry
- Children (under 18): Data will be retained until the individual turns 25 years old, or 7 years from the last entry, whichever is longer

These retention periods ensure compliance with the **Privacy Act 1988 (Cth)** and relevant state legislation such as the **Health Records Act 2001 (Vic)**. After the retention period, data will be securely disposed of or archived in accordance with approved data governance protocols.

Contact Us

If you have questions or concerns about your privacy or participation in a CQR, please contact:
Email: Med-ClinicalRegistries@monash.edu
Phone: +61 3 9903 0463